The Language of Pain – Better Requirements for Pain Tools

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Abstract. We describe a co-design method for development of an assessment tool for chronic pain. Here, by taking a "research through design" approach, we visualized and shared various strands of our domain knowledge. From this, a common understanding of the relevant issues was seen to emerge, which in turn facilitated creativity among the group. Thereafter, a collective proposal for a pain assessment tool was formulated After outlining this proposal, we move on to argue that, based on our experience this method provides a useful platform for interdisciplinary collaboration in healthcare technology development.

1 Introduction

The way we organize health care today is believed to require more manpower and recourses than would be sustainable in the future. Among other things, we expect that a larger elderly populations will need increased support and service provision from healthcare bodies [1]. Finding new ways to prepare for this anticipated higher future demand is therefore becoming an urgent need.

Information and communication technology (ICT) solutions may have the potential to provide a more effective and economical platform for some health care services. Development of these services however can be complex and requires close interdisciplinary collaboration. Many ICT applications for health care are developed without sufficient collaboration between the health care professionals and the technologists who are developing the application or tool. Interdisciplinary collaboration and co-design can be both time consuming and difficult as professionals with different areas of expertise must invest time in order to learn each other's professional vocabularies, approaches and requirements.

This article introduces "the 3 cube", a way of organizing the exploratory phase of interdisciplinary work so as to provide an effective framework for collaboration and enhanced lateral thinking when developing research questions and requirements for a new tool.

1.1 The context of the Study

This study was conducted at the Institute of Design Innovation (InDI) in Morayshire, Scotland using the "3 Cubed" method. A Cube seeks to combine interdisciplinary

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knowledge with design capability and tether these aspects to specific design research agendas[1]. By including design practice within the method, the study is seen as an example of 'research through design', and so is defined as 'practice-based' [2][. In taking such an approach we are in agreement with Archer (1995), who states:

> 'There are circumstances where the best or only way to shed light on a proposition, a principle, a material or a function is to attempt to construct something, or to enact something calculated to explore, embody or test it [3].' (p.11)

Over the past two decades one of key issues of debate surrounding practice-based approaches has concerned the ways in which such research should be enacted [4]. For Zimmerman and Forlizzi (2008), motivation is seen as the primary starting point for such an approach [5]. The pair argue that design researchers tend to launch their research from within one of two motivational contexts: the 'philosophical' wherein concepts motivate, or the 'grounded' wherein a 'real-world' problem is tackled through the research (p.42). These motivations are then seen to allow the researcher to formulate a research question, which in turn directs the research.

Thus, selecting a grounded motivational context for the study, we have investigated the basic framework which is seen to underpin the design of pain assessment tools, including the core information of pain. This information is based on a minimum data set of pain information required to express and understand the severity and impact of a patient's pain [6].

1.2 An Introduction to the Theoretical Context

In spite of having consulted with a health care professional, it would appear that too many patients continue to suffer regularly from pain. Approximately one out of two patients visiting the doctor do so for pain related issues, and pain prevalence is especially high in older people, the chronically ill, as well as cancer patients [7].
At the outset, it is apparent that pain may be characterized as a wholly subjective experience. Certain clinical signs such as higher pulse and blood pressure can be associated with pain, however, there is no reliable objective measure for quantifying the pain experience for an individual. This is well illustrated by the linguist Elaine Scarry who writes that "having pain may come to be thought of as the most vibrant example of what it is to 'have certainty', while for the other person it is so elusive that 'hearing about pain' may exist as the primary model of what it is "to have doubt" [8].

An alternative approach may be found in the work of two Canadian researchers, Melzack and Torgerson. The pair investigated patients' use of particular English language words as they sought to describe a painful stimulus. From this data, they

[1] In 'tethering' interdisciplinary knowledge and design capability to design research agendas one of two approaches are generally applied. Either a process of 'research into design' is taking place, wherein design practice is theorised, or alternatively a 'research through design' approach is applied. Within a Cube, a research-through-design approach would see the designer researcher and the interdisciplinary researcher/practitioner sharing a common goal and thus involved in a collaboration. In collaborating, both seek to benefit from the others' expertise and eventually, to contribute to their own specific fields of enquiry.

formed categorizes around common themes and showed how a patient's description of their pain experience may in fact provide detailed information of the possible pathophysiology of pain [9]. This assessment tool has translated into several languages and as such may be thought of as a template for a universal "the language of pain" [10-14].

Many questionnaires have been developed for self-assessment of pain, which both standardize the information and minimize the variation of descriptions. The aim of these is to help clinicians to quantify and understand the symptoms described by their patients. Pain research and improvement of pain management has led researchers to develop further pain assessment tools, with the result that there currently is a large number of pain assessment tools available to a clinician [4-6]. However, in spite of this apparent abundance, pain prevalence has not improved very much over the last number of years [7]. Indeed, it might be argued that the development of pain assessment tools does not appear to lead to more effective pain management in the long run although we are assuming a link between better description of pain and better treatment. Research has shown that for some patients, the existing pain assessment tools are not easy to use and include inappropriate contents for many subgroups of patients. Ultimately, as Scarry, Melzack et al. and others have identified, there is no uniform, structured method of communicating pain experience [8, 15]. The development of a structured way to communicate this experience would be by definition a language, and thus the language of pain [14-17]. Within this study then the language of pain is defined as *a uniform, structured method of communicating the experience of pain*.

2 Method

Our study applied InDI's Cube method as a means of investigating its subject (see section 1.1 above). Within this application, three domain experts from the fields of medicine, computer science and visual design,, were brought together to focus on the predetermined subject of 'the language of pain'. Thus, a collaborative working model was established at the outset. A time frame of three meetings was suggested as a guide, however it was assumed that the group would be otherwise self-organizing [18].

During the Cube process, in order to consider their subject as well as share perspectives, the team applied the following design-based techniques:

- Theme Exploration through Sketching;
- Model Development;
- Concept Development;
- Expert Review;
- Concept Refinement;
- Question Formulation.

2.1 Theme Exploration through Sketching

After an initial period of sharing around the three researchers' individual areas of expertise, the study proper began with a session focusing on theme exploration. This exploration took the form of team members sketching and so sharing a variety of concepts and understandings. These related to the subject of pain, the practice of visual design and a consideration of different research approaches.

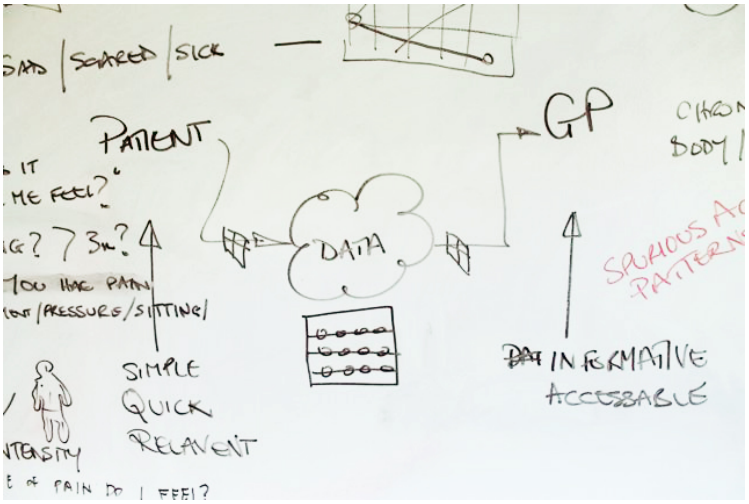

Fig. 1: Visualisation of Ideas and Knowledge

2.2 Model Development

Having shared knowledge relating to pain, visual design and the conduct of research, the next step was to visualize how the process of pain communication is performed with focus on information transfer and processing of data. Here, via sketching, the process of information transfer was visualized in a Unified Modeling Language (UML) diagram which was refined through several iterations [19]. This part of the discussion was an interactive and iterative process dependent on domain knowledge from all three domains.

2.3 Concept Development

Having devised this model the team then began to consider how a pain assessment tool might fit within the aforementioned 'learning space'. That is, the team began to

approach the problem from a pragmatic perspective seeking solutions to an identified ‘gap’.

2.4 Expert Review

With the sketches to hand, the team requested a review from a pain specialist. Within the review the sketches acted as a platform from which the specialist was asked to imagine on the one hand their usefulness and other the other alternative applications for the proposed tool. Based on the review feedback, two strategies presented themselves as alternative trajectories for the project. The team could either further define the design parameters for the proposed pain assessment tool or else review and reflect on their work thus far. The team chose the later.

2.5 Concept Refinement and Question Formulation

Here, through a process of focused scrutiny, involving a mapping of the entirety of the research project, a new view of the project emerged. In developing this overview it was possible to identify key items that had emerged in the process. This led to the formulation of a specific research question.

3 Results

The main outcome of this interdisciplinary exploratory study was the design-hypothesis that by embedding learning in a pain assessment tool one might increase a patient's pain literacy as to improve their pain management. This idea presents a new way of thinking and extends the range of possible uses for a pain assessment tool.

3.1 Theme Exploration

In approaching the notion of a ‘language of pain’ our study was initially directed via a philosophical motivational context. The concept was based on creating an universal language for pain communication based on Elaine Scarry [8] and Ronald Melzack's [9] research . However, due to the team’s structure it was soon approached from a problem-based motivational context. This was related to the context of pain communication and barriers related to proper pain management. The team soon moved beyond its initial philosophical motivational context and defined a grounded context, i.e. problem-based space, from which to operate. Here focus was directed to pain assessment tools. The domain expert set out the ‘problems’. The first task was to explain pain in general terms with regard to pathophysiology of the nerve stimulation to the perception of the stimulus in the brain [15].

3.2 Model Development

The communication process was determined to involve two participants: a patient and a physician. Between both a ‘communication space’ was seen to emerge. Here, the etymology of communication was invoked so as to emphasize its underlying notion of ‘sharing’ something ‘in common’ between both parties. Within this framing, it was noted that the patient seeks to ‘express’ and ‘articulate’ their pain. Through the application of this approach it was revealed to the team that the physician is, in turn, required/requested to ‘interpret’ the patient’s expression and articulation of their pain. Here, the patient is afforded the opportunity to learn through feedback from the “assessment tool” and from the physician. Equally, in evaluating the patient’s response to their interpretation, the physician is also afforded an opportunity to learn. Thus the communication space was seen to become an active “learning space”.

It is within these spaces of communication and learning that we conceptually placed a device. It is intended that information about the patient's pain could be visualised in layers which contain more and more detail related from the outer layer with a minimal level of information needed in order to describe the pain experience and understand the pain severity to the most detailed level of pain experienced. In this way the patient could be seen to be describing the landscape of their pain in a similar way to the way in which a map of different scales describes the physical landscape around us.

In addition to the level of detail in which the experience of pain is described there is also the possibility to use this “communication space” to describe the experience of pain over time.

The communication of pain is thought to be a continuous and dynamic process based on a few core domains (e.g., intensity, location, temporal pattern and pain quality) which can shed light on the impact of pain and the etiology of pain [9]. All the pain domains may not need to be communicated each time but have to be clarified and investigated each time there is a major change in the pain perception. In order to verify changes in pain perception, a databank of previous pain assessments should be available, confirming pain assessment as an ongoing continuous process.

Pain was then categorized into acute and chronic pain. Chronic pain was subcategorized into chronic non-cancer pain and chronic cancer pain. The information was also categorized and grouped into “need to know” domains in order to treat pain [6]. Further domain knowledge was investigated based on pain communication in a patient/doctor relation.

3.3 Concept Development

Using sketches a series of design concepts were generated wherein various possible digital and analogue approaches were proposed. These approaches were framed around a set of pre-determined pain parameters, with various possible forms emerging as the sketches evolved and iterated. Through group reflection it was decided that one particular form—a wheel based model—might be particularly appropriate for

patients. This model was sketched further with digital and analogue versions being set out.

3.4 Expert Review

The pain specialist was intrigued by the idea that pain information from the patient could be processed by the assessment tool and also used to give tailored feedback to the patients. He suggested including guidelines for pain self-management in the feedback. There was no equivalent model in the existing pain assessment tools commonly used in his clinic and he thought this concept was interesting.

3.5 Concept refinement

Returning from the expert review the team held their final meeting. This meeting centered critically and reflexively evaluating the progress of the study thus far. Here, the 'ideal' nature of the communication model that has been proposed was identified. That is, the team recognized that this model presents an idealized version of how communication might proceed. In particular it was identified that an implicit assumption was that physicians were both able to, and wanted to provide a clear interpretation of the patient's articulation of their pain. This was an assumption for which we lacked either direct or indirect evidence. Therefore, it was decided to target the physician's perspective and so test whether the model had validity among this user group.

3.6 Question Formulation

Through the above concept refinement the following research question was formulated: *How can learning be embedded into a pain assessment to tool so that patients improve their pain literacy, and the physicians improve their pain management.*

4 Discussion

The embedding of learning for both patients and health care providers represents a shift to a new model of pain communication, which focuses on both participants in the pain communication. Evidence from clinical studies has identified lack of knowledge among clinicians and patients as one of the barriers to good pain management [17, 20, 21]. By including targeted pain information which aims to promote learning for both clinicians and patients we hope to facilitate better pain communication and thus better pain management for patients with chronic pain.

Within our study, the notions of 'assessment' and 'communication' have been intertwined. Here, pain communication is considered a process of making pain

common, as well as a learning process. If communication allows for assessment, and assessment for management, then it would follow that good communication is at the very core of good management.

Traditional assessment tools can be looked upon as examples of a clinician-centered model focusing on serving the clinicians' need for information. The traditional models of pain assessment provide standardised information collected from the patient and delivered to the healthcare provider. Unstandardised but tailored information is in turn fed back to each patient [9, 14, 16]. The input from the patient is used to assess the patient's need for pain management offered by the clinician. The content of the information from clinician to patient is based on a problem based conversation [6, 22, 23]. The constellation of the conversation is undergoing a change from a patriarchal to a shared decision making [22, 23]. Within this change more focus is needed on providing sufficient health literacy for patient. The inclusion of standardized feedback which aims at increasing the patients' health literacy could enable a learning process which in turn could support patients to take a more active part in the treatment of their pain and open up a greater self-reliance in the process. The Scottish government has recently released a new health literacy policy which places this as an important issue for health service and health practitioners [24]. We believe this model can provide a better understanding of the problem and facilitate the transfer of knowledge between two domain experts: the patient and the health care provider. Pain management can in this way become a collaborative process between patients and healthcare providers.

As stated above, this research question related to the extension of common pain assessment tools and was developed through an interactive process with three domain experts. The method applied in this project was based on a 'research through design' approach. Here, rather than taking a standard 'co-creation' approach, e.g. [8], which links designers with users, in the Cube method links designers are linked with domain experts. In this way, areas of key concern within the particular knowledge domains may be directly addressed. Thus, together, the designer and the domain experts are able to explore issues through the application of design practice within a research context [18]. As such, the method seeks to administer pathways towards radical innovation, over slight incremental change, as has recently been the goal in product development over the last two decades [9, 25]. This process is supported by information transfer through the visualization of the domain knowledge and concepts relevant to the research context. Additionally, the project's overall trajectory is shaped by its pre-specified timeframe.

In this case, the method may be seen to demonstrate good applicability for development in the field of health care due to the structured framework, which might be easier to follow especially when coming from a science background. Solving problems arising from within philosophical and real-problem motivational contexts necessitates that team members work to gain a clear understanding of the broader situation in order to develop new ideas which might then be proposed. The focus on the 'whole situation' and not only the "tool", may be seen as supporting lateral thinking. Additionally, the formulation of a research question as a part of the process puts emphasis on the fact that the idea must be tested in order to assess its validity.

The original timeframe of this process (3 days times 3) was not strictly adhered to, but keeping the iterations short enough to prevent information overload and long

enough to make sure the important information was communicated to the team was important. The common understanding of the participant's domain knowledge early on in the process was crucial and enabled the team to consider the current process and make new suggestions from early on. This framework challenged traditional ways of working and enabled lateral thinking for creating healthcare solutions. The result of the collaboration is the suggested new concept for pain communication which hopefully represents a step towards a more sustainable pain management process

5 Conclusion

The interdisciplinary collaboration within the "3 Cubed" method enabled us to make use of our domain knowledge to create a new idea for a pain assessment tool. It is envisioned that this proposal may be lead to a tool which can be used for assessment of pain, as well as supporting the patients' development of pain literacy and improving the health care providers' pain management skills at the same time. In devising this proposal, the "3 Cubed" method has provided a good platform for effective teamwork, dissemination of knowledge and the direction of specific domain knowledge into the generation of new ideas.

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